



Trust of social media content and risk of making misinformed decisions: Survey of people affected by cancer and their caregivers[☆]

Ilona Fridman^{a,*}, Carma L. Bylund^b, Jennifer Elston Lafata^a

^a Lineberger Cancer Center, University of North Carolina, USA

^b The University of Florida, College of Medicine, USA

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ABSTRACT

Background: This study explores social media (SM) usage and trust in information among cancer patients and their caregivers. We compare socio-demographic characteristics to identify groups more likely to rely on social media for treatment decisions and those less inclined to validate social media information with their provider. **Methods:** A national survey of people diagnosed with cancer and those who were caregivers to people diagnosed with cancer was conducted via online survey in November–December 2021. Socio-demographic factors associated with respondents' use of SM and comfort disclosing SM use were assessed using logistic regression.

Findings: Out of 262 respondents, 65% were likely to use SM to make decisions about lifestyle changes, cancer screening, vaccination, cancer treatment, medical testing, or choosing a provider. SM users were younger ($OR_{adj} = 0.11, p < 0.01$), identified as Black ($OR_{adj} = 10.19, p < 0.01$), and had less education ($OR_{adj} = 0.86, p = 0.02$). Those with less education reported not being comfortable discussing SM with their providers ($OR_{adj} = 1.25, p_{adj} = 0.01$).

Discussion: Results contribute new understanding of the digital divide, highlighting the need for not only improving access to digital information but also the need for a supportive environment that provides patients with dependable methods to verify the authenticity of the information they encounter.

1. Introduction

Social media (SM) significantly influences various aspects of our lives, including health. SM refers to internet-based platforms that enable individuals to establish user profiles, connect with fellow users, and share and exchange various forms of content [1]. Previous research has shown that people use social media to inform their medical decisions. A survey conducted by the National Cancer Institute reports that about 16% of US adults, approximately 37 million people utilize information from social media (SM) in their medical decision-making processes [2]. High demand for health information might increase the use of SM. For instance, during the COVID-19 pandemic, when people needed more information to protect their health, a survey showed that the proportion of people trusting social media for health-related information was 23–27% [3]. A serious diagnosis such as cancer might also increase individual interaction with health information online. For instance, a study showed that up to 80% of patients with cancer used SM for

connection with peers. For 49% of them, the cancer diagnosis was an impulse to initiate the use of SM [4]. In the current study, we explore in detail what social media platforms individuals with cancer and their caregivers use and find trustworthy for informing various types of medical decisions. We also offer a comparative analysis of their demographic characteristics to identify subgroups of people who may be more inclined to use SM for health information.

The use and trust in SM information may pose some risks for cancer patients and caregivers. Inaccurate information on SM can misguide medical decisions, leading to harmful outcomes. Inaccurate information or misinformation is defined as information not supported by current scientific evidence or expert consensus [5]. A recent systematic review reported that 40% of SM posts related to health contain misinformation [6]. Another study showed that 30% of cancer-related posts contained misinformation, among which 77% contained harmful information that could delay seeking medical attention, lead to economic harm, have toxic side effects, or harmful interactions with standard cancer

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* Corresponding author at: 450 West Dr, Chapel Hill, NC 27599, USA.

E-mail address: ilona_fridman@med.unc.edu (I. Fridman).

treatment [7]. The prevalence of misinformation may be even higher for content about prevalent cancer types. For example, about 70% of YouTube videos [8] and most popular SM reposts about prostate cancer [9] were found to contain misinformation. In the case of breast cancer, 51% of social media posts contained misinformation [10]. Misinformation has been shown to negatively impact beliefs and decisions. Up to 40% of the population in the USA holds the belief that cancer can be treated solely with natural therapy [11]. Individuals who adhere to these beliefs and opt for natural cancer therapy in conjunction with standard therapy experience a reduction in their survival rates [12,13]. A recent study revealed that those who decided to try exclusively natural therapy after being diagnosed with cancer witnessed a decrease in their survival rates by a factor of 2.5 [14].

Numerous programs have been initiated to combat misinformation. Some of these programs aim to identify and eliminate misinformation from SM [15], while others concentrate on educating users about responsible information search [16]. These programs, however, require time and effort to reach the end users of SM information. A more readily accessible form of protection against misinformed medical decisions might be a consultation with a healthcare provider about the information a patient finds on SM. The current recommendation from the National Institute of Aging to those impacted by cancer is “When in doubt, ask your health care provider about what you read” [17]. However, conversations about the information patients discover outside clinical settings are infrequent. For instance, while 50–77% of patients with cancer use complementary therapies, [18,19] up to 77% of them do not have any discussion about it with their oncologists [20]. Moreover, those patients who used SM to inform their decisions and shared SM information from SM with their healthcare provider encountered overt or implicit opposition [21]. To inform intervention development and target group identification, the secondary objective of this study is to assess the level of comfort that diverse patient populations and their caregivers feel about sharing information they find on SM with their healthcare providers.

2. Methods

2.1. Recruitment and procedures

In November – December of 2021, we conducted a survey in collaboration with Qualtrics panels, distributing it to a nationally representative sample of randomly selected US residents who are at least 18 years old. In completed responses, we identified respondents with a cancer diagnosis or serving as caregivers. The study received IRB approval with a waiver of informed consent from the University of North Carolina at Chapel Hill. Respondents were informed about study procedures, privacy, and confidentiality before taking the survey.

2.2. Measures

The survey assessed respondents’ trust in six social media (SM) categories. The categories were developed based on the work of Huo and Turner [22]. Each category, such as “media sharing” (e.g., YouTube, Pinterest), was defined with examples. Respondents rated trust in each category on a 4-point scale. They then evaluated the likelihood of using SM for 7 categories of medical decisions on a 5-point scale. The categories of the decisions were informed by Ofstad et al. [23] and the HINTS survey [24]. Comfort discussing SM information with providers was rated on a 5-point scale. The survey also gathered socio-demographic data: age, gender, race, ethnicity, sexual orientation, education, and household income. The survey is available verbatim in supplementary material.

2.3. Data analysis

To assess the likelihood of using SM, we created a variable called

Table 1
Respondents; demographics.

Categories	N = 262
Gender, n (%)	
Female	146 (56)
Male	112 (42)
Missing	4 (2)
Age, mean (SD)	
Missing	48 (19)
Education, n(%)	
Less than high school	16 (6)
High school graduate (or GED)	68 (26)
Some college or technical school	82 (31)
Associate degree	24 (9)
Bachelor’s degree	44 (17)
Graduate or professional degree	26 (10)
Missing	2 (1)
Race, n(%)	
Asian	9 (3)
Black or African American	31 (12)
White	206 (79)
American Indian or Alaska Native	7 (2)
Native Hawaiian or Other Pacific Islander	2 (1)
Mixed (White and Black or African American)	6 (3)
Missing	1 (0.5)
Ethnicity, n(%)	
Non-Hispanic	225 (86)
Hispanic	36 (13)
Missing	1 (1)
Income, n(%)	
Less than \$10,000	46 (18)
\$10,000 to \$14,999	24 (9)
\$15,000 to \$24,999	22 (8)
\$25,000 to \$34,999	34 (13)
\$35,000 to \$49,999	45 (17)
\$50,000 to \$74,999	27 (10)
\$75,000 to \$99,999	29 (11)
\$100,000 or more	33 (13)
Missing	2 (1)
Sexual orientation, n(%)	
Straight or heterosexual	223 (85)
Gay or lesbian	15 (6)
Bisexual	22 (8)
Prefer to self-describe or missing	2 (1)

“likelihood of using SM.” A value of “1” was assigned to respondents who indicated “likely” or “somewhat likely” to use SM for at least one category of medical decision. If a respondent selected “neither likely nor unlikely,” “somewhat unlikely,” or “unlikely” for each type of medical decision, their response was coded as “0.” To report patients’ comfort communicating with their providers we recoded the 5-level Likert scale to a binary outcome for which those respondents choosing “somewhat comfortable” and “very comfortable” were coded as comfortable “1” and other responses (ie., “very uncomfortable,” “somewhat uncomfortable,” and “neither uncomfortable nor comfortable”) were coded as not comfortable, “0.” Logistic regression was used to evaluate the association between socio-demographic factors and (1) the use of SM for medical decisions and (2) patient comfort levels in discussing the information from SM with their providers. Demographic characteristics were dichotomized where appropriate or split into tertiles (e.g. age and income).

We executed both unadjusted and adjusted models, with the latter including demographic factors as controls that are not on the causal pathway between a demographic factor of interest and the outcome [25,26]. The detailed results from the adjusted models can be found in supplementary material.

3. Results

Out of 613 respondents who completed the survey 262 were eligible for this study. Among them, 55% ($n = 145$) were caregivers for someone with cancer; 18% ($n = 46$) had a past or current cancer diagnosis; and

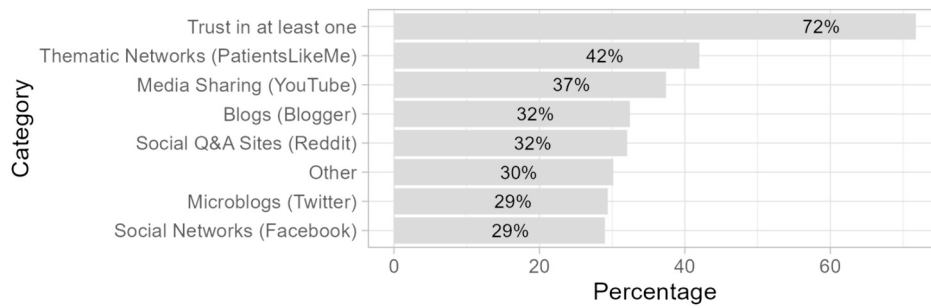


Fig. 1. Percent of respondents who trusted social media “a lot” or “some” by type of SM. The category “Others” allowed respondents to type in any source of their choice, the most frequent answers included: google or other online sources, friends, family, and offline resources.

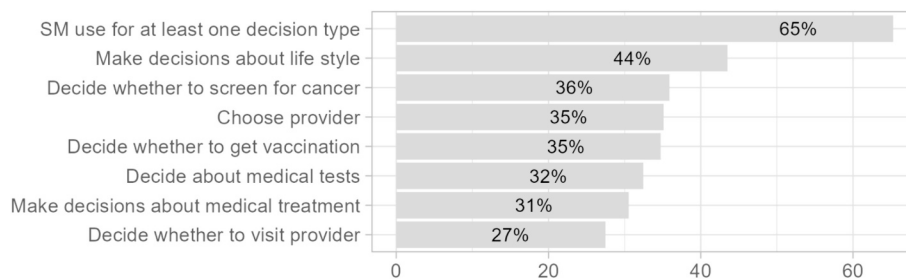


Fig. 2. Percent of respondents who were “likely” or “somewhat likely” to use social media by decision type.

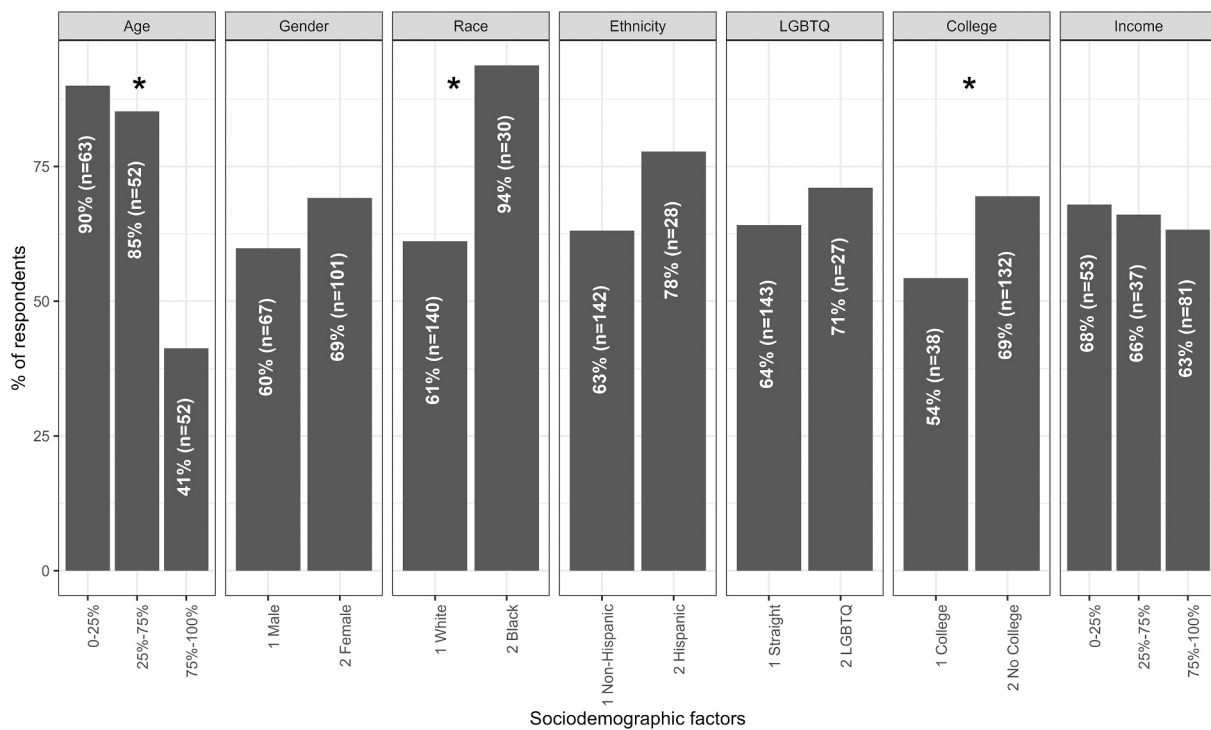


Fig. 3. The percentage of respondents “likely” or “somewhat likely” to use social media, by respondent characteristics. Total sample includes those who are likely to use SM: $n = 171$; Age tertiles include: 0–25% <30 y.o.; 25–75% 31–45 y.o.; 75–100% >45 y.o.; Income tertiles include: 0–25% less than \$25,000; 25–75% between \$25,000 – \$50,000; 75–100% more than \$50,000; * indicates significance level at $p < 0.05$.

27% ($n = 71$) had a dual role of a patient and caregiver. Respondents’ demographics are reported in Table 1.

Overall, 72% ($n = 188$) of respondents trusted at least one type of SM. Fig. 1 shows that most of the respondents 42% ($n = 108$) trusted thematic networks, such as [patientlikeme.com](https://www.patientlikeme.com). The least trusted were

Twitter and Facebook, with 29% ($n = 75$) of respondents rating each of them as trustworthy.

About 14% ($n = 37$) already used and 65% ($n = 171$) of respondents were likely to use SM to inform medical decisions. As reported in Fig. 2, almost half, 44% ($n = 114$), of the respondents suggested that they

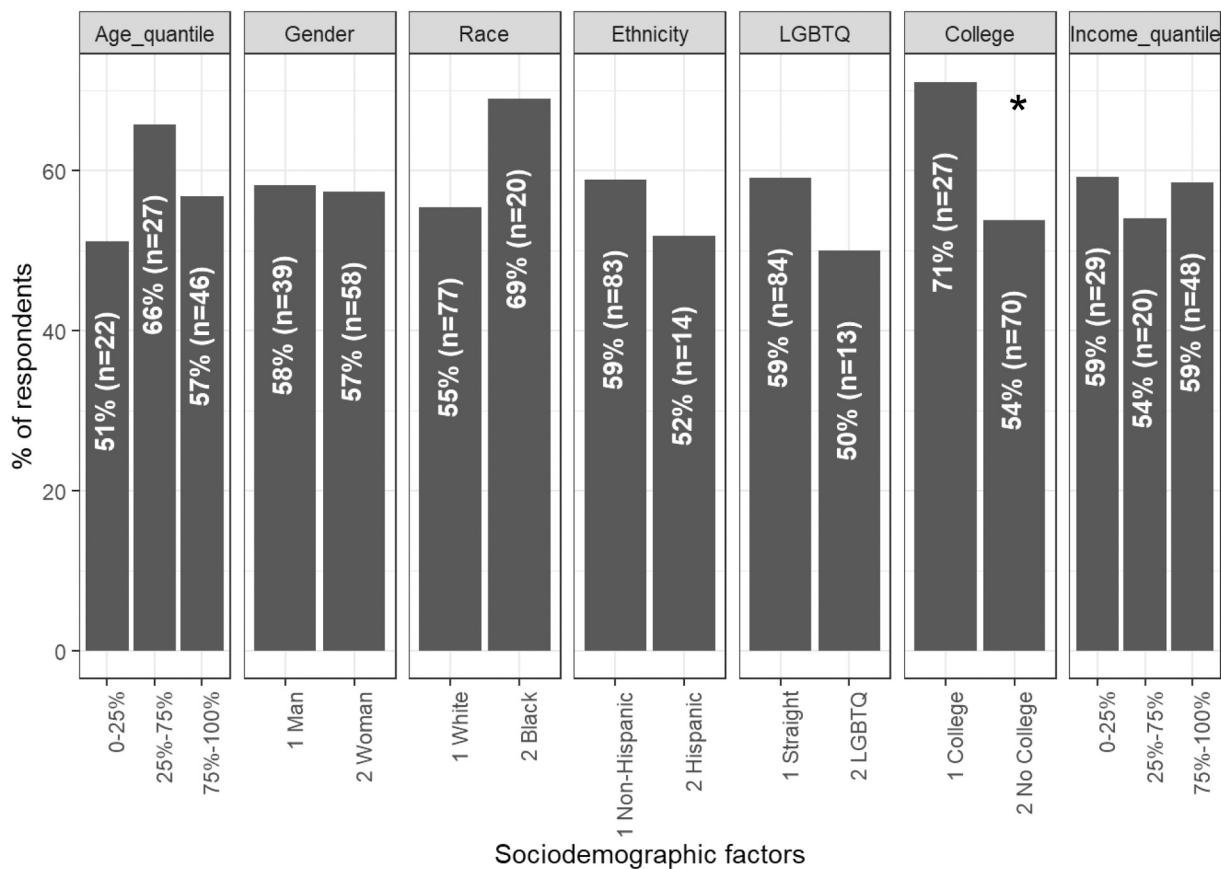


Fig. 4. The percentage of respondents who reported feeling “very comfortable” or “somewhat comfortable” sharing information from social media with their healthcare providers, by respondent characteristics. Total sample includes those who are likely to use SM: $n = 171$; Age tertiles include: 0–25% <18–30 y.o.; 25–75% 31–45 y.o.; 75–100% >45–89 y.o; Income tertiles include: 0–25% less than \$25,000; 25–75% between \$25,000 – \$50,000; 75–100% more than \$50,000; * indicates significance level at $p < 0.05$.

would likely use SM to inform lifestyle changes. The least amount, 27% ($n = 72$), of respondents said that they would likely use SM to decide whether they needed to visit a provider.

The respondents’ likelihood of informing medical decisions with SM varied between populations as reported in Fig. 3. Those who were more likely to inform medical decisions with SM were <45 years old ($OR_{adj} = 0.11$, CI_{adj} 95% 0.04–0.27, $p_{adj} < 0.01$), Black ($OR_{adj} = 10.19$, CI_{adj} 95% 2.94–64.36, $p_{adj} < 0.01$), and no college education ($OR_{adj} = 0.86$, CI_{adj} 95% 0.76–0.97, $p_{adj} = 0.02$). Among those who said they would likely use SM for decisions, 42% of respondents reported being uncomfortable talking to their provider about the information they found at SM. As depicted in Fig. 4, respondents without a college education expressed less comfort in discussing information from SM than those with a college education ($OR_{adj} = 1.25$, CI_{adj} 95% 1.07–1.48, $p_{adj} = 0.007$). The detailed statistics and unadjusted models are presented in supplementary material for each analysis.

4. Discussion and conclusion

4.1. Discussion

The study highlighted the significant role that SM plays in the decision-making processes of people with cancer and their caregivers. As many as 72% of people with cancer and their caregivers placed trust in at least one SM source, which is consistent with previous observations [27]. Also, in this study, 65% of respondents were inclined to use SM for making medical decisions. These decisions encompass vaccination, cancer screening, and cancer treatment, all of which have profound implications for their overall well-being and life expectancy. Upon a

more detailed data analysis, we observed that younger respondents, Black respondents, and respondents without college education were more inclined to utilize SM for medical decision-making. These findings align with previous research, which documented higher levels of trust among non-White populations compared to the White population in information about COVID-19 from SM [3]. Previous and current research underscores a pressing concern: the reliance on SM engenders a heightened exposure to misinformation prevalent on SM, especially among marginalized populations who have lower trust in the healthcare system [28].

A high prevalence of health misinformation instigated various efforts [29,30] aimed at capturing and eradicating misinformation from public content. The healthcare system could support these efforts during clinical interactions with cancer patients, yet our study found that up to 42% of patients feel uncomfortable talking about the information they found on SM with their providers. Especially vulnerable were patients with no college education who were significantly less comfortable talking with their providers about SM information than those with a college education. Previous research has found that patients have various reasons for not wanting to discuss the information they find online with their providers. For instance, patients worry about doctors’ being unreceptive to the information, some have a lack of trust in the healthcare system, or a desire to save face [25]. To ensure that patients are protected from misinformed decisions, it is critical to understand why patients avoid discussions about the information they find on SM. There is also a need to equip healthcare providers with the tools and skills that facilitate productive conversations about information that patients identified on SM, particularly when the information is incorrect.

This study relies on self-reported measures. Thus, respondents might

underreport their use of information from SM as many of them felt uncomfortable mentioning it to healthcare workers. The survey was conducted online, which may have introduced a selectivity bias. Individuals who are more comfortable with technology and SM are potentially overrepresented in the sample. However, the percentage of respondents who reported using SM in past medical decisions is similar (14%) to the one (16%) reported by a nationally representative sample of US adults [2]. Since responses were collected in a nationally representative survey, the patients and caregivers of the respondents most likely are diagnosed with the most prevalent cancers and those for which survival is relatively high, including early-stage breast, prostate, lung, and colorectal cancer. Patients and their caregivers seeking information in the context of other cancers might exhibit different information search patterns. As such, care should be taken when generalizing findings beyond the current sample. Given the variability in social media (SM) usage across different types of decisions observed in this study, future research could benefit from investigating the particular decision types for which various demographic groups, especially marginalized populations, show a greater reliance on SM.

4.2. Innovation

This study is novel as it provides empirical data describing the intention to use and trust in health information from SM among diverse cancer patient populations and their caregivers. On the one hand, our results highlight new avenues for healthcare and other organizations to reach diverse populations via SM with trustworthy information. On the other hand, we identified populations who are at risk for misinformed medical decisions due to a high prevalence of misinformation on SM. These findings emphasize the importance of involving patients in transparent discussions about the information they identify via SM, especially since many of them feel uncomfortable initiating such discussions. It is critical to ensure that vulnerable patient populations have dependable methods to verify the authenticity of the information they encounter. Because of their reported disproportionate reliance on SM for medical decision making, these conversations are particularly crucial for younger patients, people who are Black, and those without a college education.

4.3. Conclusion

This study highlights the significant impact of SM on medical decision-making among many individuals with cancer and their caregivers, which pose a substantial risk to patients due to the potential of misinformed decisions. Differences in SM usage were also prevalent, especially among marginalized groups such as Black adults and those with lower education levels who reported a relatively higher reliance on SM for medical decisions compared to their counterparts. Such findings point to a need to prioritize efforts to enhance digital literacy skills, particularly among marginalized populations. Additionally, healthcare teams should aim to create a supportive environment for patients and their caregivers, facilitating open discussions that enable patients and caregivers to validate SM-derived information with experts and make well-informed decisions.

CRedit authorship contribution statement

Iлона Fridman: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Carma L. Bylund:** Writing – review & editing, Supervision, Investigation, Conceptualization. **Jennifer Elston Lafata:** Writing – review & editing, Supervision, Resources, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Carma Bylund (second author) is an editor of the journal to which we are submitting the manuscript. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2024.100332>.

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